



Mental Health and Disability Services Redesign

Service System Data & Statistical Information Integration Meeting Minutes

Wednesday, October 24, 2012

10:00 am – 3:00 pm

Polk County River Place

2309 Euclid Avenue, Des Moines, IA

MINUTES

Members Present: Rick Shults, Robin Harlow, Kathy Stone, Karen Walters-Crammond, Karen Dowell, Jill Eaton, John Grush, Jody Holmes, Cindy Kaestner, Lonnie Maguire, Sue Novak, Dennis Petersen, Joe Sample, Sue Duhn, Andrea Jansen, Ashley Moore

DHS Staff: Connie Fanselow, Lauren Erickson, Norm Edgington

Other Attendees:

Jess Benson	Legislative Services Agency (LSA)
John Pollak	LSA
Lee Hill	DHS
Laura Roeder-Grubb,	Iowa Department of Human Rights
Marissa Eyanson	Easter Seals

Report from the Outcomes and Performance Measures Committee

The Outcomes and Performance Measures Workgroup has identified six outcomes domains:

- Access
- Life in the Community
- Family and Natural Support
- Person Centeredness
- Health and Wellness
- Quality of Life/Safety

Specific outcomes to be measured will be identified within each domain. The workgroup is also developing a dashboard and determining what the important measures are that would reflect the effectiveness and efficiency of the system.

Points of consensus:

- Balancing what we want to know with what is reasonable to gather.
- Making this a key part of a quality improvement framework.
- Solving problems, not placing blame: focusing on using information to work together to do problem solving; not as an assessment that is in any way punitive.
- Gathering information that can help identify where challenges exist and being open to asking more questions to achieve improvement in outcomes.
- Recognizing that a dashboard will not answer all questions.
- Approaching questions from a collaborative quality improvement perspective.

Information to be gathered within the domains:

- Personal satisfaction data from people receiving services and their family members.
- Payment transaction data.
- Delivery of service data: information gathered from providers that is over and above what can be found in the transactional data.

For individuals receiving services:

- The precise methodology has not yet been determined – could be electronic, in person, or a combination of options.
- The use of sampling is likely.
- Would want a sample to gather information by region that is statistically valid; could come close to doing that with existing resources.
- Interested in gathering information by population group also, but that would require a much larger sample to be statistically valid.
- It would take a significant investment to raise the sample size to make it valid for individual population groups, for example, it is estimated that:
 - For state level validity a sample size of 400 to 500 would be needed;
 - For regional level validity a sample size of 4800 to 5000 would be needed; and
 - For validity by region and population groups served the sample size would probably need to be at least 12,000.
- The cost would escalate significantly as the sample size increases.
- The recommendation of the Outcomes Workgroup was to start with gathering information by region and set the higher level of specificity as a future goal.
- Conversations with people at the University of Iowa who are experienced in this kind of sampling are continuing.

Information could be directly entered into a central data system:

- The state, regions, and provider organizations would have access to the centralized data in a variety of ways.
- Data could be de-identified.
- The questions asked would depend on what information is wanted.

Types of data collected and reported:

- Penetration rate – measure of how many people get services.

- There is also another group of outcome measures that would probably not be in any simple claims transaction system, and the workgroup has not yet examined how to gather that type of information.
- Interested in the setting where people live, their employment status, and aspects of person-centeredness.
- Information gathered might include survey data, transaction data, and other information that is not a part of the claims system.
- Putting level of care and claims transactions together in one place could answer a lot of outcome and performance measures at the provider level.

Discussion:

What thoughts does this group want taken back to the Outcomes Workgroup?

- Surveying would emphasize quality of life data.
- IDPH currently gathers data by interview at admission, discharge, and six months post-discharge.
- The universe for sampling would probably be the number of persons who were served through the county system last year.
- It doesn't make sense to spend a lot of resources collecting this kind of information for people who only receive short-term intermittent treatment; will want to focus on those who are receiving services over time or on a more consistent long-term basis.
- The system has far more influence over the outcomes of people who receive a high level of services and supports, than it does over the outcomes of those who receive fewer supports.
- Most people receiving services on a long-term basis have a case manager, health home, county service coordinator or someone in a position to know the person's situation and have an ongoing relationship with that person who could gather information, although this group is probably less than one-third of the total number of people served.
- Need to avoid survey fatigue from people who get tired of participating too often, and avoid duplication.
- Need to include experts to help address some of these questions.
- Want a streamlined survey for most people, and possibly a more in-depth survey for a few (similar to the U.S. census model).
- Need to identify a methodology that minimizes cost while providing for integrity of the data, and must recognize that it will always be a snapshot in time.
- Are we measuring the individual effect of treatment or the overall effectiveness of the system? Either way we are measuring the impact of services.
- Gathering data may be different for different groups of people.
- Information needs to be collected with a use in mind and needs to be valid for the purpose it is collected.
- Providers also need to buy into the process and trust the results.
- Need to be cautious about extracting data by provider; it may not be statistically valid at that level.

- Currently transaction data does not identify voluntary vs. involuntary hospitalization; if that information is important then decisions will have to be made about how it should be gathered.
- Users should be provided with tools that allow them to pull data for the uses intended.
- May need to limit the ability for users to do ad hoc queries because data will not be valid for unintended purposes.

Preliminary Draft Report:

Group discussed the [draft report](#). Some final work on client identifier and management of data still needs to be done.

Section III – Workgroup Recommendations

“Entities within the MHDS system will not be required to use the same operational/transactional system.” (page 2)

Discussion:

- Should add the flexibility to use what already exists.
- Add language around improving efficiency by making other systems more broadly available and reflect the pitfalls of using a single system.
- Change first sentence in last paragraph on page 2 to “. . . recognize that there may be some entities that would benefit from moving to a single system . . .”
- First paragraph, second sentence – CPCs and case managers are not “entities” – should be reworded.

“Operational/transactional systems need to have the capability to be linked and exchange information. This information needs to be labeled consistently and have the same definition.” (page 3)

Discussion:

- Define “entity” since it is used throughout the document. Use the list used under “data landing zone” on page 3 and add state agencies and regional administrators.
- Change to “submit” data rather than “report” data.
- Under item 3 – not sure core data and extended data examples are clear – could repeat what the report said about it.

“The central data repository should match client information from different sources to the same client using a unique client identifier.” (page 4)

Discussion:

- The Iowa Code specifies the client identifier; should get this changed to a less specific code requirement.
- Want to provide the assurance of keeping confidentiality but perhaps with more flexibility in crafting the identifier.

“Privacy and security needs to be maintained consistent with defined roles and responsibilities.” (page 5)

Discussion:

- Are we glossing over who can access information?
- Need to be clear on what is allowable and what is a violation of privacy while respecting client confidentiality.
- Needs more work/come back to this discussion later.

Section IV – Limitations to Workgroup Recommendations

Discussion:

- Should some reference be made to cost? There will be costs associated for modifying systems and developing stand-alone transactional systems.
- Legislators have been clear that if something costs more we need to quantify it and tell them how much it will cost

Patient Matching Overview – September 2012

Members reviewed a [PowerPoint handout](#) that described the process for how the Iowa Health Information Network (IHIN) works. It matches client fields and identifiers in real time. The handout includes a flow chart diagram of patient matching flow.

- How do we blend into this in a way that is consistent with our report?
- There are federal restrictions on what can be shared (a one-page summary from “Frequently Asked Questions: Applying the Substance Abuse Confidentiality Regulations to Health Information Exchange.”)
- Federal law is more restrictive related to what can be shared for substance abuse treatment data and state law cannot supersede federal.
- How does it work with the Health Information Exchange (HIE)? It should work similarly here as well.
- Iowa is going to be an “opt out” state, which means all records will be included unless a person specifically opts out.

Review of [Senate File 2318](#):

Sec. 14. NEW SECTION. 135.156E Legal and policy.

13. Unless otherwise provided in this division, when using the Iowa health information network or a private health information network maintained in this state that complies with the privacy and security requirements of this chapter for the purposes of patient treatment, a health care professional or a hospital is exempt from any other state law that is more restrictive than the Health Insurance Portability and Accountability Act that would otherwise prevent or hinder the exchange of patient information by the patient’s health care professional or hospital.

Discussion:

- Indicates that specifically for the purposes of patient treatment, a health care professional or hospital is exempt from any other state law that is more restrictive than HIPAA and speaks to getting information from other providers for the continuity of care.
- Noted that very cautious attorneys may advise providers that under Iowa Code Chp. 228 they cannot contact a payer for prior authorization without written consent from the client, although most providers use verbal implied consent. (Chp. 228 has to do with contacting insurance companies in connection with mental health treatment information.)
- The provision quoted above seems to help facilitate exchange of information between providers but not with community planners or regions; a different solution will be needed for that.

Privacy and Security Concepts for the Report:

- What do we want to tell readers of the report about privacy and security needs and the ability to share information among users?

Discussion:

- We must meet federal rules, especially regarding substance abuse treatment data and HIPAA.
- We must meet any state laws or seek changes to them (have identified Chp. 228.7(1)).
- We need to know what the data model will be in order to develop a privacy/security policy.

For Discussion:

Do we want to strive to meet the requirements that are in the HIE so that the new exception from state restrictions discussed earlier can be used? Would there still have to be additional legislation since it specifies sharing information for the purposes of patient treatment?

Discussion:

- Is data for purposes of care coordination considered patient treatment? Collection of de-identified data would go beyond patient treatment.
- Explore and consider using the privacy and security rules that are in the IHIN (Iowa Code Chp. 135).
- Need to ensure access for administrative and coordination purposes; expansion of Code provisions may be needed.
- Need access to more than very global numbers to make good use of data.
- Acknowledge the complexity of ensuring client confidentiality and privacy.
- Need to more clearly define the roles of state, region, etc.

For Discussion:

How do we answer questions and operationalize the system? Who is responsible for moving forward with this?

Discussion:

- Build on the principle of extracting data from different systems, putting it into a central data warehouse, and making it available for use.
- There should be a discussion of policy before it gets to the technical development stage.
- It should be done hand-in-hand with the design and development of the warehouse.
- Establish a group to guide the policy operation of the warehouse following a set of principles.
- Could have a policy group and a technical group, or one combined group to work on development.
- Cite the substance abuse treatment requirements contained in federal regulations.
- Need participation agreements about how data will be used and shared.

For Discussion:

Where should the warehouse reside? Who should be responsible for it? How should it be governed? Who owns the system? To what extent does Iowa code direct these decisions?

Discussion:

- Ownership means where the system is housed and who is responsible for servers, software, day-to-day operation, etc.
- It will be a collaborative effort with ongoing decision making and guidance.
- It will have both technical and policy aspects.
- Could be a state agency, regional consortium, ISAC, outside vendor?
- It will require some resources; if a legislative appropriation is needed, it should be a state agency.
- The state is ultimately responsible and has to warehouse all sorts of data.
- There should be a policy group established for setting it up; they could also become a steering committee or governance board.
- There should be an overall governance body that is held accountable for the operation of warehouse; either within the state agency or working in tandem with the state agency.
- There could also be an advisory council with an executive committee to the governance body that represents constituents (those who contribute data) and other stakeholders.
- Any group outside the agency that is charged with the work would be advisory.
- Will want to get feedback from system users.
- Consumers and consumer advocates should have a voice in policy making.
- Also need legal advisors; probably the Attorney General's Office.
- The E-health Executive Council could be used as a model.
- Group consensus is that an advisory body should have valid input; not just a rubber stamp.
- It would be challenging for a state agency to delegate its authority in absence of specific Code Provisions.

- This is MHDS Redesign and that is the purview of DHS; it should belong to DHS as the agency responsible for publicly funded mental health and disability services. Related rulemaking through the MHDS Commission.

Other considerations:

- Make sure to identify all stakeholders and include them in the process.
- Make establishment of the governance group one of the first activities and discuss the implementation steps and timeline with them.
- Need to identify the cost to state government and recognize the costs outside of state government.
- Need to provide technical assistance to the entities who will be providing data and using the system as part of the governance process.
- Will there be a phase-in, depending on costs, and if so, who determines that?
- Some counties that have diverse systems are looking at coming together in regions; is this a mechanism for helping bring those systems together?
- Counties should have the ability to pull and use their own info out of the system.
- Advice to Outcomes Workgroup: Keep it simple.

Next Steps:

MHDS will be working on:

- Taking this information and incorporating it into a new working draft of the workgroup report; rewriting some sections and adding some new ones including timelines and work plans, including both data and outcomes and anything else that ties in from other workgroups.
- Identifying what goes away and changes in Iowa Code or administrative rules regarding any of those requirements.
- Establishing a baseline for the status of core services statewide.
- Having conversations with experts at the University of Iowa to answer questions about statistical validity.

The workgroup:

- Conference call is scheduled for Nov. 27, from 10:00 am to noon; there will also be a meeting room reserved locally for anyone who wants to attend in person.
- A revised draft of the report will be shared with workgroup members prior to the phone conference
- Will walk through the draft section-by-section and review each part to make sure there is group consensus, or note any issues where there may be some disagreement.

For more information:

Handouts and meeting information for each workgroup will be made available at:
<http://www.dhs.state.ia.us/Partners/MHDSRedesign.html>.

Website information will be updated regularly and meeting agendas, minutes, and handouts for the Redesign workgroups will be posted there.